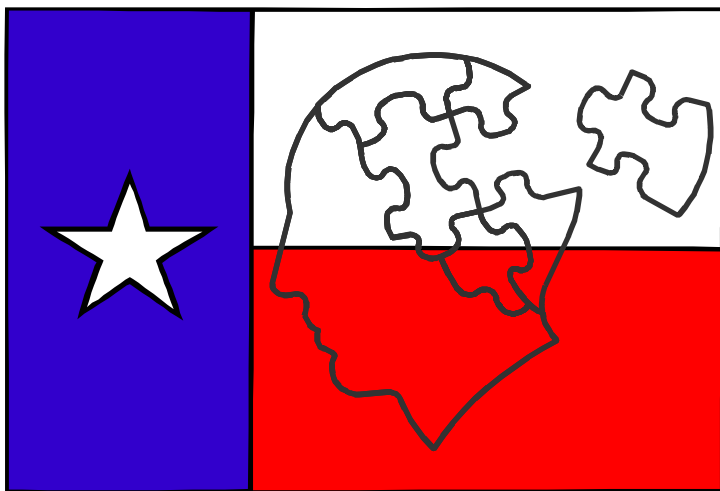


# **Traumatic Brain Injury (TBI) In Texas:**

## **The Silent Epidemic**



## ***Putting the Pieces Together***

**Texas Traumatic Brain Injury Advisory Council**  
December 1998 – Updated December 2001

## Every 4 minutes

of every day a Texan will sustain a traumatic brain injury.

## Every half hour

a Texan will be hospitalized due to traumatic brain injury.

## Every hour and twenty minutes

a Texan will be permanently disabled by traumatic brain injury.

## Every 2 hours

a Texan will die from a traumatic brain injury.<sup>1</sup>

**More people are disabled by TBI than by spinal cord injury, Alzheimer's, Cerebral Palsy and Multiple Sclerosis combined.<sup>3</sup>**

*Traumatic brain injury ranks among the most serious public health problems in the United States. Each of us is vulnerable to a traumatic brain injury. Yet, as a society, we are barely beginning to recognize and discuss what is virtually an epidemic of brain injury.*

William J. Winslade, Houston

*Confronting Traumatic Brain Injury*, Yale University Press, 1998

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# **TBI: The Silent Epidemic**

## ***Putting The Pieces Together***

### **Executive Summary**

**Findings from statewide public meetings – Spring, 1998,  
Needs Assessment Survey Responses, and a Policy Analysis  
of Texas' Health and Human Service Agencies**

**Presented by the**

**Texas Traumatic Brain Injury Advisory Council**

The quotations and comments in this document are from Texans who attended the public meetings in the spring, 1998, responded to the Needs Assessment Surveys or otherwise have submitted comments in writing to the Council. For further information or copies of the Policy Analysis and Results of the Needs Assessment Surveys and Public Meetings, please call: 512-458-7111 ext. 3069.

“I was on my way home from work on that crisp February afternoon. Anticipation was in the air. Tonight would be the first time since the birth of our 4 month old baby that my spouse and I were going out. A romantic dinner was planned ... it was Valentine’s Day.

I remember looking ahead of me and noticing the traffic was building up on the two-lane road. A car was stopped, signaling for a turn. I heard a bang and then nothing...

Weeks later and 40 miles from home, I was emerging from a coma. I had no memory of the “jaws of life” used to extract me from the car or of the helicopter flight.

I had no idea I was so close to death.



Half of all TBIs  
result from motor  
vehicle crashes.<sup>4</sup>

All I could feel was confusion, fear and pain. Who were all these people in my room? I didn’t recognize any of them. I was told these were the people closest to me ... my family. I didn’t even know my own name.

Some of the effects of the brain injury were obvious. I could no longer walk without stumbling. I couldn’t find the words I needed to communicate and I knew these were familiar words. Every time I tried to eat, I choked on my food.

I found myself getting angry over insignificant things. I couldn’t remember the simplest instructions or directions. I was experiencing things as a result of the brain injury that were invisible to anyone who came into casual contact with me.

In a split second, I was one of the thousands of Texans each year who become traumatically brain injured. Almost everything I knew of myself was altered that day. My life and my family's lives have forever changed as a result of the brain injury.

There is no pill, no shot, no technology that can cure a brain injury.

While much has improved over the past two years, my previously well defined and productive life has been shattered. My family is adrift... my spouse is struggling to cope and support the family on one income. I need constant supervision and assistance.



TBI accounts for more years of lost productivity than any other injury.<sup>1</sup>

I remember my 'old self' and sometimes wonder where 'I' went. I can't remember where I put things or what I was about to do. It's such an embarrassment when I become teary-eyed over nothing. At the same time, I am in awe that my family still loves me.

I wonder, "Can anybody hear me?"

There has to be some help out there somewhere. How am I going to find it? Will I ever go back to work? I feel isolated and alone...

My story isn't obscure or one of a kind. I am one of hundreds of thousands of people living with traumatic brain injury in Texas."

## It's Number One...

Traumatic brain injury is the number one cause of death and disability among children and young adults. Annually, one and a half times more people die from brain injuries than from AIDS, and eight times more people are diagnosed with traumatic brain injury than with breast cancer, and 34 times the number of new cases of HIV/AIDS each year.<sup>1</sup>

[Even though] I am an Emergency [Medicine] Physician...I wasn't prepared for the call "Your daughter has been in an accident, they're taking her to the trauma center...[she is in a deep coma]"...she lived another 48 hours after sustaining a brain injury. "The Call"...still burns in my memory today. Mother, Houston

Annually, 144,000 Texans sustain a traumatic brain injury. Of these people, over 4,200 will die and over 5,700 will have a permanent disability from the brain injury. Since modern medicine has developed extraordinary life-saving techniques over the past 25 years, more people are living with brain injuries now than ever before.



Every dollar used for brain injury rehabilitation saves up to \$35 in future medical costs.<sup>3</sup>

## What are the Costs?

Although the brain injury strikes the person, the after effects create a shock wave of issues impacting the whole community. This is costly...in altered or lost lives, enormous personal suffering and tragedy, lost public revenues and increased public expenses. Brain injury costs Texas hundreds of millions of dollars each year.

## What are the Challenges?

Traumatic brain injuries happen ... There is no time to sit down and discuss it as one might with an illness. Second opinions are not an option. Brain injury is not an illness that can be healed with a pill. It is not a broken body part that is mended with a cast.

When my child was discharged from the hospital...we were on our own. Mother, El Paso

People with brain injuries and their families are thrown into panic, frustration, and despair as they generally have no idea what to do next or where to turn for help.

Help! Where do I go from here?

Person with a traumatic brain injury, McAllen

This cry is all too common after a brain injury. Those immersed in living with a brain injury face question upon question as they seek out the needed rehabilitation and long term supports after brain injury.



How are services funded?  
How do we access them?  
How long will the services last?  
Are they appropriate services?  
Who will pay for them?  
Where can I turn for help?

Those who have private insurance find it is very quickly exhausted. Needed therapies and long-term supports may not be covered at all. Persons with brain injury and their families are forced to turn to publicly funded resources, supports and services—each with its own mission, goals, and eligibility criteria.

[He] was not eligible [for assistance] because he was 25 when he was injured. Whenever I learn about a program...they all require that he be injured before age 22 or 18...What's the magic in those two ages?

Mother, Richardson

## However ...

- The service delivery system is fragmented, is spread across many state agencies, and lacks coordination.
- Most services are extremely difficult to access and each has its own eligibility criteria.
- Many programs have waiting lists that may be “years” long. Each program is designed to serve very specific conditions or needs into which someone with a brain injury “just doesn’t fit”.

## What's the Need?

People living with brain injuries require early intervention, appropriate consistent care, long-term supports and services. The absence, delay, or interruption of needed services can cause further trauma to the individual and the family.



30,000 children and youth are disabled by TBI each year.<sup>4</sup>

My 16 year old daughter was critically injured in a car accident..Once she was released from inpatient rehabilitation we began to experience multiple problems...She could not be left alone. Family training and counseling [was] needed. Insurance didn't cover this...Families are financially devastated by the brain injury.

Mother, Jacksonville

For those who survive the traumatic brain injury and their families, life as it was known is forever affected.

[We] face many obstacles, emotional issues, loss of self worth, confidence, self-esteem...we are robbed of our identity.

Person with a brain injury, Houston

For some, the changes may be profound with life-long disabling conditions. For others, the initial injury may have been less severe, but the effects are life altering and unimaginably difficult.

I look okay, but I'm not functioning okay.

Person with a brain injury, Lubbock

Regardless of the severity of the injury, rehabilitation and long-term supports and services are necessary for all persons who become brain injured.

My son does not have mental illness, but he has mental deficits. People with brain injuries had a "before life" ...they remember what they used to be. They have a lot of failures and frustrations that are likely to continue unless [they receive] appropriate intervention.

Parent, Dallas



## Rehabilitation and long-term supports and services offer hope for a productive life...

Rehabilitation and long-term supports and services provide individuals with brain injuries, their families, their communities, and therefore, the State of Texas, the ability to confront the growing public health crisis resulting from traumatic brain injury.



Fewer than 1 in 20 people who suffer a TBI get the rehabilitation they need.<sup>3</sup>

## What will make it happen?



A coordinated and accessible statewide system of supports and services for persons with brain injuries and their families;



Information and education about traumatic brain injury, its effects, where to get help, and whom to call;



Recognition that traumatic brain injury is a public health issue which must be addressed in Texas;



Publicly funded programs which provide appropriate supports and services for persons with brain injury and their families; and



Efforts to reduce preventable brain injuries.



# Because Brain Injury is a Forever Deal...

The Texas Traumatic Brain Injury Advisory Council's mission is to:

- Inform state leadership of the needs of persons with brain injuries and their families,
- Recommend policies and practices to meet those needs, and
- Promote prevention efforts in Texas.

In February, 1998, Governor George W. Bush established the Texas Traumatic Brain Injury Advisory Board, now known as the Texas Traumatic Brain Injury Advisory Council. The Council membership is representative of the geographical areas of Texas and comprised of individuals with Traumatic Brain Injury (TBI), family members, providers of services, and state agencies. Governor Bush, in proclaiming October, 1998, Brain Injury Awareness Month, stated: "I encourage all Texans to learn more about brain injuries and how to prevent them".

## The Council:

- Distributed statewide, 1000+ Needs Assessment Surveys to persons with traumatic brain injury, family members, service providers, and publicly funded agencies.
- Held 9 public meetings throughout Texas during the Spring of 1998.
- Completed a policy analysis of existing state supports and services.
- Published findings from the Needs Assessment Surveys and Public Meetings.
- Developed a comprehensive Statewide Action Plan of supports and services for persons with traumatic brain injury and their families.

## Ongoing Activities of the Council:

- Inform state leaders of traumatic brain injury issues and policies for meeting the needs of persons with brain injuries and their families.
- Recommend to state leaders policies and programs which more effectively serve persons with brain injury and their families.
- Explore and promote innovative approaches to providing services and supports to persons with brain injury and their families.
- Promote education, training, and information about brain injury issues.
- Advocate for persons with traumatic brain injuries and their families.
- Support activities aimed at reducing preventable brain injuries.
- Conduct outreach to obtain public input.

As a society, we are saving lives. We must be concerned with the quality of life.

Person with traumatic brain injury, Austin

The voices of persons with traumatic brain injuries are being heard by the State of Texas through the Texas Traumatic Brain Injury Advisory Council. However, the activities of the Council cannot be accomplished by the Council alone. The voices of all Texans need to be raised in support because...

## **No one is immune to a Traumatic Brain Injury!**

### **What You Can Do:**

- Become knowledgeable about the issues and concerns of traumatic brain injury.
- Support efforts to improve state policies and programs for people with traumatic brain injury and their families.
- Promote efforts to reduce preventable traumatic brain injuries in Texas.
- Call the Brain Injury Association of Texas helpline at 1-800-392-0040 if you or someone you know needs help with a brain injury

This booklet is presented as a service of the Texas Traumatic Brain Injury Advisory Council, which is responsible for its contents. Please direct questions or comments to:

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# Did You Know?

## Traumatic Brain Injury (TBI):

- Strikes over 2,000,000 Americans<sup>1</sup>
- Results in one and a half times more deaths than AIDS<sup>2</sup>
- Occurs every 23 seconds<sup>3</sup>
- Is the number one cause of death and disability of children and young adults<sup>2</sup>
- Killed more Americans between 1981 and 1993 than have been killed in all the wars in our history combined<sup>2</sup>
- Costs Americans \$56,300,000,000 each year<sup>1</sup>

## Of the People Who Sustain a Traumatic Brain Injury<sup>3</sup>:

- 1 in 2 result from motor vehicle crashes, 1 in 5 from falls, 1 in 8 from violence, and 1 in 10 from sports
- Males between 15-25 are at greatest risk
- Fewer than 1 in 20 will get the rehabilitation they need
- Most will likely “Fall Between the Cracks” in services developed for people with other disabilities<sup>2</sup>

## Annually, In Texas<sup>1</sup>:

- 144,000 Texans will sustain a traumatic brain injury:  
**1 every 4 minutes**
- 5,728 Texans will be permanently disabled by traumatic brain injury:  
**15 every day**
- 16,180 Texans will be hospitalized:  
**2 every hour**
- 4,214 Texans will die from a traumatic brain injury:  
**1 every 2 hours**

1. Centers for Disease Control & Prevention, Atlanta, GA

(Figures do not include individuals who seek treatment other than at a hospital.)

2. William Winslade, "Confronting Traumatic Brain Injury", Houston, Yale University Press, 1998.

3. Brain Injury Association of America, Arlington, VA

4. National Information Center for Children and Youth with Disabilities



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